

# Serious Illness Messaging Guide Brief

Evidence-Based Messaging Toolkit for  
Serious Illness Care



# How to use this toolkit



We built this toolkit because we want to change how the public views serious illness care - so that more people experience the benefits of our work. Based on empirical research and decades of experience, we've developed resources that can help any health communicator effectively write content and hold positive conversations with the general public about the benefits of advance care planning, palliative care, and hospice.

Our field started with the pioneering work of hospice. The hospice public message was essentially: we'll give you a good death. That public message, we have learned, appeals to a small slice of the public. But the majority of laypeople don't want to talk about dying, and their hesitation and fear have led to misconceptions about what we do.

For our field to thrive, we need to reach the people who are hesitant. So when you're talking to the public, don't start with bad news. Put your marketing hat on. Leave the super-serious talk to a clinician having a personal encounter with a patient, and look at the research we've assembled. The bottom line: when you introduce our work to the public, talk about what every person wants when they're in a tough place because of illness: a sense of control, reasonable choices, and support to get through it. This toolkit will help you speak that language.

## Whats in the toolkit

### The 5 Principles

01. Talk Up the Benefits
02. Present Choices for Every Step
03. Use Stories—Positive Ones
04. Invite Dialogue—and Not Just Once
05. Invoke a New Team

### The 5 Steps

01. Write out your engagement strategy.
02. Assess what your organization is doing now.
03. Brainstorm some tweaks, upgrades, or redo.
04. Ask your audience for feedback.
05. Share your failures & successes.

## What's in the website

We've squeezed a lot into this PDF, but you'll find much more on the [website](#) including quick guides for messaging by topic (advance care planning, palliative care, and hospice), how you can use social media and visuals, trade secrets for inclusive messaging, and much more. This toolkit summarizes experience and wisdom from

many people (you can find them on the website too), and builds on foundational work by Diane Meier and Lisa Morgan at the Center for Palliative Care--we owe them a lot (although any mistakes in this toolkit are ours!). Zawama Arenas at Flowetik and Anna Gosline at the Massachusetts Coalition for Serious Illness Care led two

research projects that we have drawn upon heavily. And we couldn't have done this without generous support from The John A. Hartford Foundation and the Cambia Health Foundation.

# We've condensed the research into 5 user-friendly principles.

We know that different organizations all have their own unique needs. The same words won't work everywhere. But the research points to a consistent set of message characteristics that engage public audiences. We used a stakeholder process to distill the research into 5 messaging principles. Then we tested them with leading organizations and focus groups. Key point: beware of writing for your colleagues, or patients who are in your care. The target audience for these messages are public audiences. And that public has not heard our nuanced views of ACP, PC, and hospice. For the most part, they don't know any of our acronyms, or language, or policies. We have to start them out more simply. To do that, we can draw on the same marketing strategies used by trusted brands and public campaigns that reduced smoking and drunk driving.

01

**Talk Up the Benefits**

02

**Present Choices for Every Step**

03

**Use Positive Ones**

04

**Invite Dialogue, and Not Just Once**

05

**Invoke a New Team**

# Talk Up the Benefits

Serious illness care improves lives. As one focus group participant said, “It gives you a handle on the illness and it broadens your mind. It takes some of the pain away, some of the anxiety away.” Messaging the point that serious illness care helps people live well is key to reaching those who can benefit from it.

Talking about the benefits is a fundamental principle of good marketing and messaging. Think about it: the messaging that you personally find appealing usually is that which speaks to you. Your specific situation, needs, attitudes. We found that when we shared the benefits of the types of serious illness care we offer with the public they were very interested. Our 100-word stories about palliative care and hospice sounded too good to be true to some of our focus group participants. But we know they’re not. In our messaging we should identify what people need and want and lead with that. To use an old hospice concept: meet them where they are. That kind of messaging will leave your target audience wanting to know more.

## What you’ll learn

- How to frame the benefits so the public will hear them
- Why leading with death, dying, and unwanted medical care is a turn-off
- Why articulating the benefits matters

## Here’s what works and doesn’t

### Instead of...

Listing all your services (which won’t tell the benefits) in med speak

### Before

Advance care planning is a process that enables individuals to make plans about their future health care. Advance care plans provide direction to healthcare professionals when a person is not in a position to make and/or communicate their own healthcare choices.

### Do this...

Highlight how the person will benefit from your services

### After

You can speak up and have a say in your care. Getting health care often involves choices that impact your life and wellbeing in different ways. Treatments only work if they work for you.

## 01. Talk Up the Benefits

02. Present Choices for Every Step

03. Use Stories—Positive Ones

04. Invite Dialogue—and Not Just Once

05. Invoke a New Team



# Present Choices for Every Step

In our focus groups, people told stories about their encounters with serious illness care. And none of the stories involved choice. Here's their default story: they're waiting in a dingy hospital conference room. A doctor they've never met comes in. And tells them that it's time to stop. There is, essentially, no choice. But wait, there are so many choices upstream from that moment! You're right. But the public doesn't know that. You can tell them.

People in our focus groups liked the idea of choice and wanted all their care choices stated explicitly -- they fear that clinicians aren't direct with them. They wanted to know their choices so they could plan their actions. But they assumed that choice referred only to disease-modifying treatments. They didn't realize that they had choices about where they could receive care, or that their decisions could factor in quality of life, or that considerations about the people they love could count. Your messaging can take advantage of this observation by emphasizing choice -- rather than acceptance or 'letting go'. Also, our focus groups embraced choice regardless of political affiliation -- this message can work in blue states or red states. People are suspicious that 'letting go' is something health care systems suggest to save money. As one person said: "It gives you a sense of control. It's what you want, not what they want. Even though they are included in it, it's what you want. Your options, and you control them."

## What you'll learn

- Why choice is so important in public messaging
- How to avoid offering choices that people won't really have
- How the idea of having a choice counteracts fears of losing control

## Here's what works and doesn't

### Instead of...

Emphasizing the worst - case scenario of not exercising choice...

### Before

Many Americans die in facilities such as hospitals or nursing homes receiving care that is not consistent with their wishes. It's important for older adults to plan ahead and let their caregivers, doctors, or family members know your end-of-life preferences in advance.

### Do this...

Illustrate how a person living with a serious illness made a positive choice that expressed an important value

### After

Carmen was healthy, until she had a heart attack. She chose a community program that dealt with her symptoms at home — so she could spend time with her husband Earl and two new grandchildren.

- 01 . Talk Up the Benefits
- 02 . **Present Choices for Every Step**
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# Use Stories — Positive Ones

Use positive and aspirational stories. Don't bombard them with statistics. A focus group participant told us "You can relate to something like this because the alternative is to explain how 72% of the people do this and 32% of them do that. I'd rather have anecdotes about people."

Stories draw us closer. Using a story, you can illustrate something in a way that's appealing and compelling. Positive stories work when people can see themselves in them -- when the story describes something they wish they could experience. So, stories about how someone with a serious illness was able to take control of their care, or get the help needed to stay at home can be compelling. Your story need not avoid end-of-life care completely, but imagine you are speaking to an inexperienced, frightened person who might find reassurance in a story showing that moments of living well are still possible. You may see public health messaging that uses stories designed to motivate people using fear. However, we know that inducing fear has not proven effective for serious illness care. That's because serious illness is threatening on its own. Telling laypeople more detail about debility, burdensome care, and painful deaths confirms their fears and amplifies their avoidance. That's why stories about positive possible futures are so important in messaging. Your positive stories can motivate the public to learn more about your services.

## What you'll learn

- Why positive stories work
- How to tell positive stories about your work
- Why negative stories work against what you're trying to achieve

## Here's what works and doesn't

### Instead of...

Trying to educate people about the differences between palliative care and hospice

### Before

For example, if an older person wants to die at home, receiving end-of-life care for pain and other symptoms, and makes this known to health care providers and family, it is less likely he or she will die in a hospital receiving unwanted treatments.

### Do this...

Illustrate a single choice and the consequences—from the patient's point of view.

### After

Later, Carmen was faced with deciding whether to have a procedure that was painful and risky. She asked if having the procedure meant she could get back to her Sunday faith services. When the doctor said she wasn't sure, Carmen chose a plan that allowed her to stay at home. That plan included hospice.

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# Invite Dialogue — & Not Just Once

Every person in our focus groups liked the idea that talking about serious illness care was a two-way dialogue. They wanted ‘breathing space’ and time to ‘let things sink in’, because their assumption is that the ‘nitty-gritty’ facts would be ‘scary.’

The idea of two-way dialogue was important to focus groups—as well as the idea that they could have space to make decisions when an immediate one wasn’t required. But they also recognized that some decisions were time-sensitive -- they just wanted a heads up. People want respect and understanding for their need to digest information in their own way. And when doctors told them that they ‘had to do’ something, they admitted resisting. So this principle reminds is to ask ourselves: is this messaging inviting dialogue? So many of our public messages in the past have been imperatives or threats (‘you’ll regret it if you don’t do this...’). Our focus reports, and other research, shows that threats don’t work. The approach that our focus groups endorsed was an invitation to get a conversation started, and then to keep it going.

## What you’ll learn

- How to emphasize that dialogue is two-way.
- Why dialogue pushes public to think upstream.
- Using dialogue counters the public assumption that they will be asked to sign forms about decisions that are binding.

## Here’s what works and doesn’t

### Instead of...

Instead of warning people about what they ‘must do’...

### Before

Patients, beware. When you’re admitted to a hospital, you’re routinely encouraged to sign a Do Not Resuscitate order, also known as a DNR. Don’t assume it will be applied only in extreme circumstances. Having those three letters on your chart could put you on course to getting less medical and nursing care throughout your stay.

### Do this...

Show a model of the back-and-forth conversation that you want to encourage...

### After

When Carmen asked if, after the risky procedure, whether she would be able to go back to church—and to walk in, the doctor said she wasn’t sure. Carmen shook her head no. Then the nurse said, “Remember when we talked a few months ago?” She reminded Carmen of a talk they had a few weeks ago, when Carmen said that when her time came, she wanted to focus on comfort, family and faith. The nurse had documented that in the chart and shared a video for her family. Carmen agreed: “That is what I said, and I still feel that way.”

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# Invoke a New Team

## Patients, people who matter to them, health care providers, & community all have a role

Every palliative care or hospice clinician knows that it takes a team to provide really good serious illness care. But laypeople don't realize that our team-based care is the standard--even though, in our focus groups, they loved the idea of having a team, and they were drawn to messaging that highlighted the value of team-based care. In addition, laypeople also recognize that the people who matter most to the patient ought to be included in the team, as well as organizations they depend on in their communities. So we can attract interest with messaging that understanding who \*really\* provides care--it's more than just the clinicians with medical degrees.

### What you'll learn

- Why invoking a new team is appealing
- How to incorporate this into your messaging.
- What not to say

### Here's what works and doesn't

#### Instead of...

Instead of pushing the 'right choice'...

#### Before

You can use an advance directive form or tell your doctor that you don't want to be resuscitated. Your doctor will put the DNR order in your medical chart.

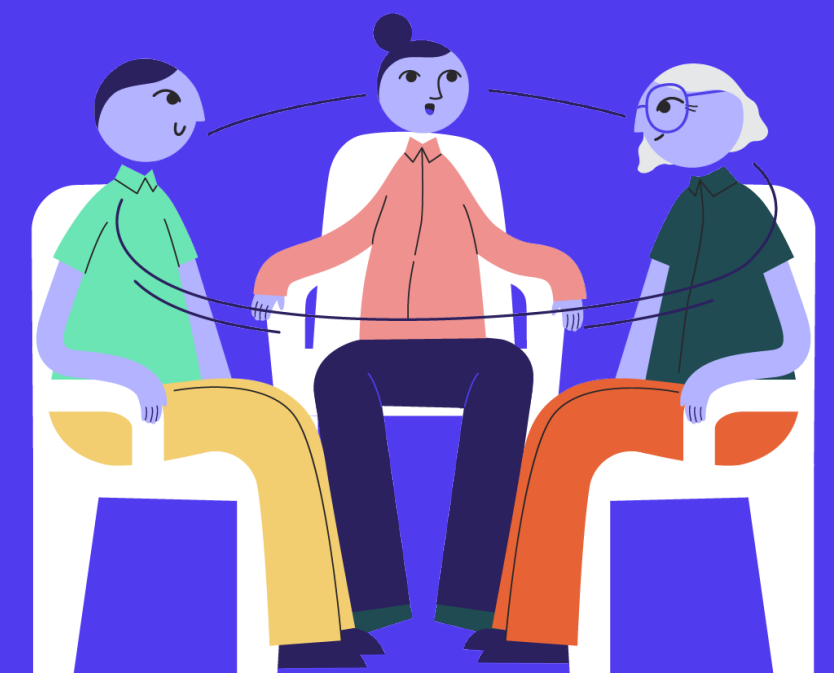
#### Do this...

Show a model of the back-and-forth conversation that you want to encourage...

#### After

Show a patient saying to their clinician: "I saw this video about the benefits of palliative care during a serious illness, about how it helps people and their families get through it. Could you refer me to palliative care?"

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# Advance Care Planning

## What you'll learn

- How to talk about advance care planning in an appealing way
- The evidence behind this approach
- What not to say

For the past 30 years we've talked about advance care planning the same way: people should just do it. It's a gift to their loved ones... And you know what? That's not working and we have recent evidence to suggest why. If we want more than a third of Americans to participate in this process, and we've been stuck at that level for decades, we need to change how we talk about this. And calling it "end-of-life planning" is definitely not the way to motivate people.

In 2019 the Massachusetts Coalition for Serious Illness did ground-breaking attitudinal national research about why people do and don't engage in advance care planning. That research confirmed that a third of the public was willing to engage in this process but that the two-thirds that don't have good reasons for not engaging. Reasons that have not been overcome, or even addressed by our talk about the practicality of planning of doing this as a gift for one's loved ones. Subsequent research with people from various diverse communities also confirmed that they understandably have a trust issue with this process that we need to acknowledge when talking with them about advance care planning. So, get rid of those old scripts and see below better, and evidence-based ways, to talk to the public about this important process.

## Here's what we know works and doesn't work when talking about advance care planning

The idea behind advance care planning is what resonates: it's about choice

### Instead of...

Leading with a complicated definition

### Before

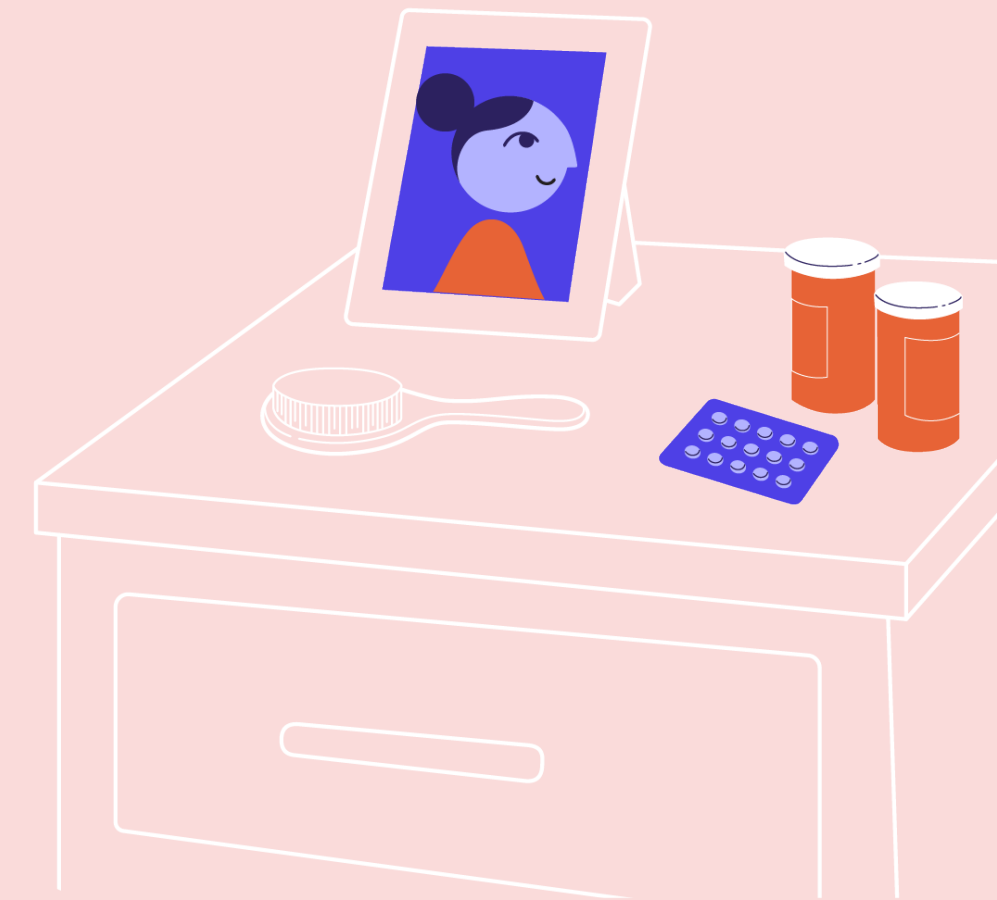
Advance care planning is a process that enables individuals to make plans about their future health care. Advance care plans provide direction to healthcare professionals when a person is not in a position to make and/or communicate their own healthcare choices.

### Do this...

Highlight the benefit to that person (not the system)

### After

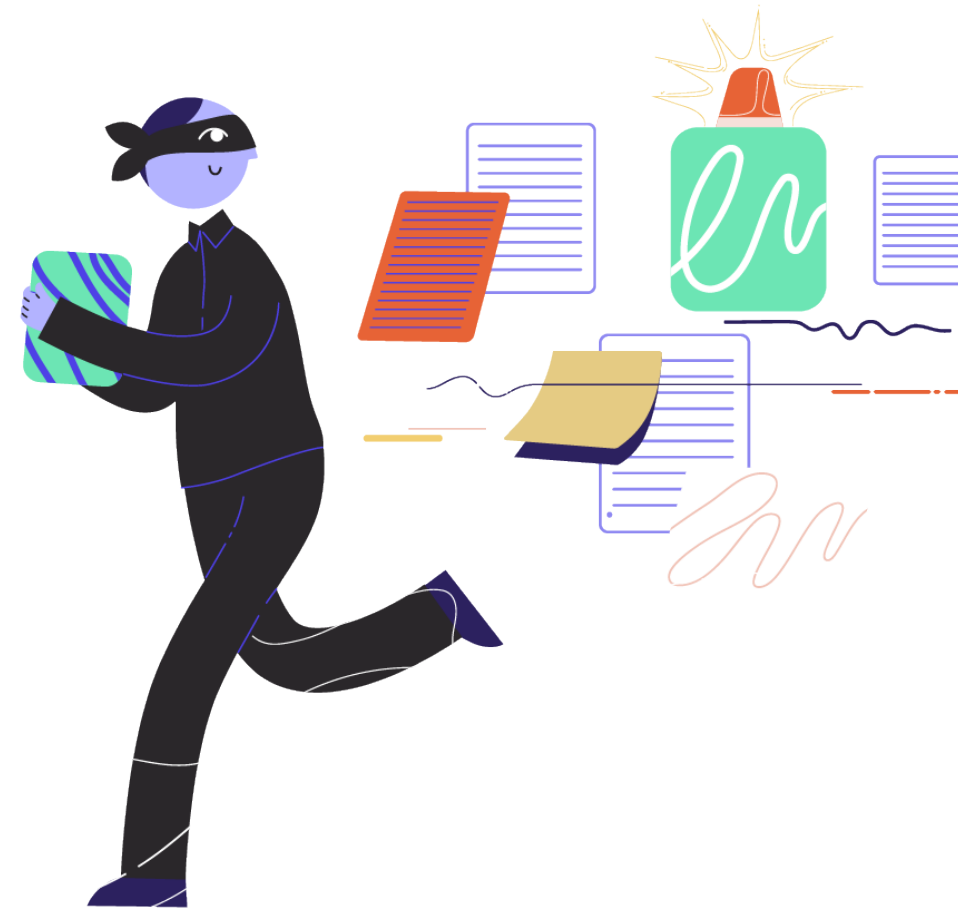
You can speak up and have a say in your care. Advance care planning puts you in the driver's seat.



# Steal These Messages

All of the messaging in this section is copyright-free. No royalties. No restrictions. Copy and paste as you please, and bring these to life in whatever ways you need.

We've taken the time to write evidence-based messages that you can just copy and paste. Whether you want to steal as-is, edit slightly to fit your organization's needs, or use as inspiration, these messages are meant for you to take. Our only ask is that you take the time to really understand how the five messaging principles come into play here in the words both present and absent. Our hope is that these messages will be brought to life through your organization's communications and ultimately, be used to better connect with the public about advance care planning, palliative care, or hospice services.



## Advancing Care Planning

**You can have a say in your care.**

Treatments only work if they work for you.

For more messages check out our [website](#)

## Palliative Care

**An extra layer of support.**

You can have quality of life while getting treatment for a serious illness.

For more messages check out our [website](#)

## Hospice

**We'll be there when you need us.**

Our team will support you—whenever, wherever, however you need us.

For more messages check out our [website](#)



# The Importance Of Inclusivity

## Why serious illness care isn't eagerly received

For historically oppressed and marginalized groups that have been denied healthcare, been mistreated by healthcare, or experienced disrespect, messaging what serious illness care can do is tricky. For many people in these groups, the injustice is something they've experienced directly. So the idea of messaging 'avoiding unwanted treatment' can strike them as irrelevant. The core issue that messaging needs to address is trust. Can your messaging indicate that your services will treat them with respect, and offer what they really need. In a large national survey, members of the public who were Black, Hispanic, and Asian were more likely to say that they were treated disrespectfully by their provider, and more likely to say they did not know what they needed to do next. Until we can meet people from these groups where they are -- coming from a place of suspicion -- they will not opt for serious illness services.



# Contact us!

## We'd love to hear from you.

Share your experience with this toolkit  
and help us make it better.

[Seriousillnessmessaging.org](https://seriousillnessmessaging.org)

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The  
**John A. Hartford**  
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